

# **Developmental Disabilities Waiting List Report July 1, 2003 through June 30, 2004**

**An Annual Report on the Demographics and Public Policy Issues**



**February 2005**

**Prepared by the Division of Senior and Disabilities Services  
Department of Health and Social Services**

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## **About this Report**

Under AS 47.80.130 (6)(d), the Department of Health and Social Services is required to operate a Waiting List and provide an annual Waiting List Report to the Governor and specified legislative committees when there is not adequate funding to meet the needs of people with developmental disabilities who would be eligible to receive state-funded services under [AS 47.80.100](#) - 47.80.170. The full text of the statute governing generation of this report is found in attachment A and each Section of this report matches the specific requirement in the law.

As noted elsewhere in this report, Alaskans who experience developmental disabilities may receive a variety of services administered and funded by multiple federal, state and local agencies. No centralized database exists to easily determine what services, if any, a person on the Waiting List is currently receiving, how services a client is receiving relate to the client's needs as expressed in the client's Waiting List Criteria Assessment form, or whether the services requested are needed immediately or may be needed sometime in the future.

Therefore cost projections contained in this report should at best be considered estimates to use in planning and not a computation of the costs of comprehensive services that may be necessary to meet the needs of each person on the list.

### **Section 1: The Purpose of the Developmental Disabilities (DD) Waiting List**

The DD Waiting List is a tool used to gather information regarding people who have been determined eligible for developmental disability services and used to select people for enrollment in services when resources are available. Additionally, the DD Waiting List assists the Division of Senior and Disability Services in planning for the future needs of people having a developmental disability. At least annually, the Division contacts those on the List to update personal information about changes in their condition or family circumstances.

Eligibility for the Community Developmental Disabilities Grant (CDDG) program is defined under the provisions of AS 47.80.900 (7). The term "developmental disability" means an individual with a severe, chronic disability that:

- is attributable to a mental or physical impairment or combination of mental and physical impairments;
- is manifested before the individual attains age 22;
- is likely to continue indefinitely;
- results in substantial functional limitations in three or more of the following areas of major life activity:
  - self care;
  - receptive and expressive language;
  - learning;

- mobility;
- self-direction;
- capacity for independent living;
- economic self-sufficiency; and
- reflect the person's need for a combination and sequence of special, interdisciplinary, or generic assistance, supports or other services that are of lifelong or extended duration and are individually planned and coordinated.

Examples of types of developmental disabilities are mental retardation, cerebral palsy, autism, and seizure disorder. Mental illness and Fetal Alcohol Syndrome may also be developmental disabilities. However, the disability must result in substantial functional limitations and meet the other criteria in the definition in order to qualify as eligible for the CDDG program.

## **Section 2: Placement on the list and the Criteria for Ranking and Selection**

In order for a person to be eligible for the DD Program they must fill out an Eligibility Determination application (Attachment B). This form provides the information needed for a DD Program Specialist to determine eligibility. In addition to the Eligibility Determination application, a Waiting List Criteria Assessment (Attachment C) must also be completed. This process is outlined in Attachment F.

The Assessment asks about an individual's current living situation, need for services, and desired services. The questions attempt to measure immediate need and circumstances that might make a person vulnerable to crisis. A provider agency, Care Coordinator, or a Regional Program Specialist can assist a person or their family member with completing these two forms. Once a determination of eligibility is made, the applicant is notified of the results and placed on the DD Waiting List. The DD Waiting List is maintained in the Central Office by staff located in Juneau, Alaska.

If a consumer's life situation changes significantly, a revised DD Waiting List Criteria Assessment may be submitted. Some types of life changes, such as the death of a parent or the individuals declining health, may put the person at risk of institutionalization. Consequently, a "reassessment" may increase the original score.

### **Scoring Criteria used for Managing the Waiting List**

A person's DD Waiting List score is figured by adding the results of the Assessment of Need and the credit for the length of time a person is on the Waiting List. The maximum points from the DD Waiting List Assessment of Need are 225. For a total not to exceed 60 points, an applicant also receives one point for each month they are on the list.

Each person's standing or rank on the list is relative to the scores of all others on the list. Consequently, a person's rank order can change depending on the relative needs of others on the list.

In order to understand the scoring associated with Waiting List Criteria Assessments, refer to the scoring definitions located after each of the five questions on the enclosed attachments.

Twenty points are automatically awarded for question #5 about adequate supports if no other questions are answered “yes.” An additional point is then awarded for the first month’s wait time. The maximum number of points a consumer can receive is 285. This is only possible if the individual fully meets the criteria of all five questions and gets the maximum 60 points for their months on the list.

The form uses a numerical assessment of need; consequently the higher the need, the greater the number of points given. For example: if the consumer is a documented threat to him/herself or others, homeless, or among a category of individuals prioritized for services by a legislative appropriation, 100 points are allocated toward the total score.

### **Selection Methodology for placing Persons on the Waiting List**

Using the method of ranking described above, selection from the DD Waiting List is based on who has the highest need and who has been on the list the longest. The number of people selected is limited by the amount of appropriation from the legislature including limits on enrollments in the MRDD Waiver. Besides an increase in legislative appropriation, resources may become available when a person leaves the DD Program or a family does not utilize all the resources allocated to them. Quarterly reviews are conducted with DD providers and grantees to identify and allocate available funds to others in need of services.

“Highest Need” can be defined as those consumers whose circumstances are determined to require immediate and comprehensive long-term supports. After all else has failed, intermediate interventions have been tried, and the need for long-term care persists, individuals may be selected from the Waiting List according to following “Highest Needs” criteria that may place them at imminent risk of harm:

- Those who are in imminent risk of substantial harm or significant regression;
- An individual living in an unsafe or unhealthy circumstance;
- An individual whose medical or behavioral needs are creating a hazard;
- An individual without supports who is at risk of involvement with the Justice System;
- An individual at risk of institutionalization in a psychiatric hospital, nursing home, or jail who would be unable to live in the community without supports, or
- An individual living with a caregiver who no longer is able to continue in that capacity such as in the death of a parent.

### **Limitations of Current Waiting List Data**

At the end of Fiscal Year 2004 (FY 04), there were 1002 people on the DD Waiting List. The list is dynamic, in that it is constantly revolving. Even though people come off the list, their numbers are replenished by people being born with disabilities, becoming disabled as a result of accident or illness, or requiring care that families can no longer provide.

As discussed elsewhere in this report, it is important to note that 82% of the individuals on the Waiting List (825 of 1002) are 22 years of age or younger. These children may be receiving various support services through other programs. In FY04, 1736 infants and toddlers were enrolled in the Infant Learning Program (ILP). Of these, nearly 78% (1350) are in the Part C Program and likely to qualify as having a developmental disability. In October, 2003, school districts reported 4354 students with DD ages 3-22 enrolled in Special Education (see page 10).

These children may be on the Waiting List in anticipation of the need for more comprehensive services some time in the future such as Respite Care, which is not available under the ILP or Special Education Assistance programs. For example, the person who has been on the Waiting List the longest was added June of 1991. This person was two years old and the family was receiving some services from one of the local DD Grantees. The family asked that their child remain on the list until there is a need for more intensive services after graduating from school.

FY 04 records show that 784 (78.2%) of the individuals on the list were receiving support or services from Community DD Grant Programs.

### **A Demonstration Project to Improve the Waitlist Process**

In FY 04, the Division initiated a project to demonstrate that a new method of financing DD services can be used to allocate funds to remove individuals from the Waiting List.

The Bethel/Wade Hampton Census Area was chosen for the demonstration because the region is representative of rural and remote regions of the state, Yukon Kuskokwim Health Corporation is a Tribal 638 entity, YKHC's desire to participate in the project, the desire of the waiver providers in the census area to increase statewide the number of DD clients served, and YKHC's leadership and demonstrated ability to successfully bill the Medicaid program for services provided.

As resources were identified, people on the DD Waiting List in the YKHC region and statewide were invited to participate in this demonstration project. Those with the highest needs according to their Waiting List Assessment Score were the first contacted. To be selected off of the list, clients in the YKHC region must choose to receive services from YKHC and remain in the region as long as it is determined by the state that YKHC can meet the clients' needs.

To start the project, 44 Medicaid DD waiver clients were transferred to the YKHC as their Medicaid DD services provider effective April 1, 2004. By YKHC providing the Medicaid DD services to these 44 DD clients nearly \$1,252,235 of the estimated FY05 care plan costs are shifted to solely federal funding. Of that amount freed up, \$626,118 will be available for DD waiver service use in the Bethel/Wade Hampton Census area.

As of July 1, 2004 there were 74 people on the DD Waiting List in the Bethel/Wade Hampton Census area. Of those, 45 were in service receiving Community DD Grant funded services. Of those in service, 7 with Individual Annual Plans (IAP) and 10 with Core Plans (CP) were enrolled in the MRDD Waiver beginning July 1. The result is that \$73,070 in

grant funds is available in FY 05 to increase hours of service or serve new people in the area through the Community DD Grant now administered by YKHC. Another 3 people have been selected off the Waiting List because they experience “Highest in Need” criteria.

Using these funds in agreement with YKHC, DSDS plans to select up to an additional 21 individuals off the Waiting List in the YKHC area by the end of FY 05. The actual number of people selected off the Waiting List will depend in part upon the capacity of the service provider organization (YKHC) to meet the needs of additional recipients in plus those already being served. This will bring us to a total of 42 new DD clients from the Waiting List into Medicaid waiver services in the area.

### **Section 3: Basic Demographic Information**

Age. Once consumers begin to receive services from the DD Program, the need for services often continues throughout their lifetime. This is a consideration to keep in mind when authorizing services to consumers still in the school years.

For program planning it is important to note that 82% of the individuals (825 of the 1002) on the Waiting List are 22 years of age or younger. In general, these are children or young adults who may benefit most from Family Support services such as Respite Care. Even though they may be on the DD Waiting List, 1,350 infants and toddlers with DD received the full benefit of ILP services and 4354 students with DD ages 3 - 22 were enrolled in Special Education in FY 04. Respite Care is a DD Program Service and is not available through the Infant Learning Program or Special Education. That is one reason the parents of these children have them determined DD eligible and placed on the List at an early age.

Young adults ages 18 – 22 aging out of school-based services often need assistance and support to participate as an adult in the community. They may benefit from Supported Employment or Day Habilitation and most do request these services.

Program records indicate that all of the 12 individuals on the Waiting List over the age of 50 receive health coverage and have access to Personal Care Assistance from Medicaid. The oldest person on the List is age 66.

<b>Age Range</b>	<b>Number</b>	<b>%</b>
0 to 3	89	9
4 to 17	567	57
18 to 21	148	15
22 to 64	197	19
Over 65	1	0
Total	1,002	100

Gender. On June 30, 2004, there were 615 males (61%) and 387 females (39%) on the Wait List. This statistic matches the gender distribution consistent with the national prevalence

rate for developmental disabilities. There are more baby boys born with developmental disabilities than girls.

Geographical Distribution. Where a person lives does not seem to be a significant factor in the distribution of those on the DD Waiting List. The table below shows the number of people on the DD Waiting List according to the DD Program Regional Office responsible for services in the person's home community. This distribution generally matches the state's census for these regions.

<b>DD Service Regions</b>	<b>People</b>	<b>Percent</b>
South-central Region includes Anchorage Area, Mat-Su, Kenai Peninsula, PW Sound, Kodiak, Aleutian Chain, and Dillingham	731	73%
Northern Region of Fairbanks includes the Interior, Bethel, and NW Alaska	190	19%
Pacific Coast Region from Cordova, Haines, Sitka, south to Ketchikan	81	8%
Total	1,002	100%
* Regions were realigned during FY 04		

Race or Ethnicity. Because race and ethnic background has not been considered when determining DD eligibility or in the selection process from the Wait List, this information was not collected in FY 03 and we are unable to report the race or ethnicity at this time. In order to enroll individuals in services provided by Tribal Entities, this information will be gathered in subsequent years

#### **Section 4: Needs and Preferences of those on the Waiting List and the Estimated Cost**

On June 30, 2004, there were 1,002 people with developmental disabilities on the Wait List. Most people request more than one service. As noted earlier, the DD Program has developed an array of residential care ranging from supporting people in their own homes or the homes of their parents, to out of home placements. Residential Habilitation, the formal definition of various kinds of residential care, is the need most frequently requested by those on the Wait List. Of those on the list 46% (456) requested some form of Residential Habilitation. Although less expensive than institutional care, residential alternatives are the most expensive form of service administered by the DD Program. By definition, a person with a developmental disability needs sequential lifelong services.

The other services requested in the order reported by people on the List are Respite Care (417), Supported Employment (223), Care Coordination (169), Day Habilitation (135), Specialized Equipment (109), Intensive Active Treatment (training or consultation for difficult behaviors) (44), Accessible Transportation (34), Chore Services (11), and Environmental Modifications to a person's home for accessibility (12).



## Projected Annual Cost

Based upon the responses for types of services requested by persons when they complete a DD Waiting List Assessment, the following annual cost projection is shown on page eight. These cost projections should at best be considered estimates to use in planning and not a computation of the costs of comprehensive services that may be necessary to meet the needs of each person on the list. In accordance with state law, the DD Program attempts to tailor services to meet individual needs. Because the services that people receive are the result of individualized planning, determining the exact cost of meeting the needs of those on the DD Waiting List is difficult.

**Table Reflecting the Projected Annual Cost**

Type of Service Requested	Number of Requests	Average Annual Cost*	Projected Costs of the Service
Group Home for Adults	47	\$79,975.00	\$3,758,825.00
Supported Living for Adults	166	\$48,850.00	\$8,109,100.00
Family Habilitation (Foster Care)	10	\$39,500.00	\$395,000.00
Shared Care	10	\$18,230.00	\$182,300.00
Supports in the Person's Home	237	\$26,250.00	\$ 6,221,250.00
Cost of Requests Residential Care	456		\$18,666,475.00
Respite Care	417	\$5,070.00	\$2,114,190.00
Supported Employment	223	\$11,990.00	\$2,673,770.00
Care Coordination	169	\$2,030.00	\$343,070.00
Day Habilitation	135	\$11,670.00	\$1,575,450.00
Specialized Equipment	109	\$2,200.00	\$239,800.00
Intensive Active Treatment	44	\$3,580.00	\$157,520.00
Accessible Transportation	34	\$2,600.00	\$88,400.00
Environmental Modifications	12	\$4,720.00	\$56,640.00
Chore Services	11	\$2,930.00	\$32,230.00
Cost of Requests for Supports			\$7,281,070.00
<b>Cost of all Requested Services</b>			<b>\$25,947,545.00</b>

- Costs for Services are figured at the FY 03 average rates paid for MRDD Waiver Services.

## Section 5: Number of Individuals Selected or Removed from the Waiting List in FY 04

Between July 1, 2003 and June 20, 2004, 29 people with DD were selected for more Comprehensive Services. Another 33 had their needs met by another program, moved to another state, or died, and 708 were names removed from the Waiting List because they did not provide the Division with information required to stay on the list.

## **The Reasons People Were Selected or Removed from the Waiting List in FY 04**

<b>Reason for Removal from the DD Waiting List</b>	<b>Number</b>
Removed as Non-responsive to DD Program Contact	68
Selected for Comprehensive Services	29
Removed as Needs Met by Another Program	9
Removed as Moved to Another State	18
Deceased	6
Total	130

It is the responsibility of the applicant to keep DSDS informed of their current contact information. Should someone be selected from the List for comprehensive services and fail to respond to notification, they can be removed from the List. If these applicants do contact DSDS after a prolonged absence from the state or after being taken off the list, they may with proper documentation be placed back on the List as of the original date they were first deemed eligible. Many people were returned to the List under these conditions.

During FY 04, the DD Program selected a total of 29 consumers from the DD Waiting List for comprehensive services or long-term care. Those who were selected had the highest scores on the Waiting List because a crisis situation placed them at risk of harm that could not be addressed with short-term assistance measures.

There were 9 individuals who were removed from the List after their needs were met by other programs. Of these, 1 was placed in the Children with Complex Medical Conditions Waiver Program. The CCMC Waiver did not operate a Waiting List in FY 04. However, it is good practice for professionals assisting children with special needs to explore all possible resources to help them. For these children, putting them on the DD Waiting List was prudent but unnecessary.

Another 8 people who were on the list in FY 04 preferred the services funded by the Adults with Physical Disabilities Waiver or obtained needed services from Mental Health or Vocational Rehabilitation agencies. Once they were enrolled in those programs and their needs met, they were removed from the DD Waiting List.

Other individuals were periodically removed from the List for various reasons such as moving to another state (18) or they died (6) as a result illness or accident unrelated to their needs for more comprehensive services or long term care.

### **Length of Time on the Waiting List**

The capacity of providers to serve new individuals, workforce shortages, family participation in planning and designing the services they receive, and availability of resources are all

factors that affect how long a person is on the list before they are selected for more comprehensive services or long-term care.

In FY 04, the average length of time that a person was on the DD Waiting List is 3.06 years.

## **Section 6: The Number of People on Waiting List 90 Days or More**

Of the 1,002 people on the DD Waiting List, 949 or 95% have been on the list for 90 days or more.

## **Section 7: Number of Students with Developmental Disabilities in Special Education**

It is important to note that Special Education and the services provided through the DD Program are different. Special Education provides specially designed instruction by School Districts. The DD Program provides for services and supports in the person's community or in the home that enables the individual and their family to avoid institutional placements and participate in community life. For those who qualify, Special Education is an entitlement. The DD Program operates within the limits of annual legislative appropriations.

According to the Department of Education and Early Development (DEED), there are about 17,998 students age 3 to 22 in Special Education. Among these Special Education students, 4354 may have developmental disabilities. Examples of types of developmental disabilities are Mental Retardation, Cerebral Palsy, Autism, and Seizure Disorder. Children with Severe Emotional Disorder or Fetal Alcohol Syndrome may have a developmental disability if they experience substantial limitations in functioning.

The numbers below reflect DEED categories for students with mental retardation, other health impairments, deaf/blindness, multiple disabilities, autism, traumatic brain injury, and developmental delays for children under the age of 9. If severe enough, these are conditions that likely could meet the definition of a developmental disability (see page 2 for more information about the definition of a developmental disability).

As of October 24, 2004, the Department of Education and Early Development reports that:

- the number of students in Special Education with developmental disabilities graduating from high school with a regular diploma was 92;
- the number of students in Special Education with developmental disabilities dropping out of high school by age 22 was 36; and
- the number of students in Special Education with developmental disabilities who by age 22 do not graduate from high school with a regular diploma but receive a Certificate of Completion was 7.

## **Section 8: Copies of this Report are Available**

Copies of this report and the forms used to manage the Waiting List are available on the Website of the Division of Senior and Disabilities Services at <http://www.hss.state.ak.us/dsds/dd/default.htm> or by request. Anyone interested in obtaining a copy of this report with attachments may call or write:

The Division of Senior and Disabilities Services  
P. O. Box 110680  
Juneau, Alaska 99811-0620  
907 465 3165 or Toll Free at 1 866 465 3165

Attachment A:

### **Requirements for the DD Waiting List Report**

Sec. 47.80.130. Powers and duties of the department.

(d) When state funding is not adequate to meet service needs, the department shall establish a DD Waiting List for persons with developmental disabilities who would be eligible to receive state-funded services under [AS 47.80.100](#) - 47.80.170 if adequate state funding were available. The department shall, on an annual basis, review the DD Waiting List and submit a report to the governor containing the information required under this subsection. The department shall send a copy of the report to the persons chairing the house and senate finance committees and the persons chairing the house and senate health, education and social services committees and shall notify the full legislature that the report is available to all legislators. The report must

(1) describe the purpose for the DD Waiting List and the strategies used to notify persons about the Wait List, and must include a copy of the information used by the department to inform individuals and families about their rights and responsibilities under [AS 47.80.100](#) - 47.80.170;

(2) explain how an individual is placed on the Wait List, what criteria determines rank on the list, and how the DD Waiting List is used to select individuals equitably and fairly across the state;

(3) give the basic demographic information across all regions about the age, sex, and racial and ethnic background of the individuals on the Wait List;

(4) identify the level of need and preferences of the individuals and families on the DD Waiting List for the services and the supports that may be necessary to meet their needs and project an annual cost to meet this need;

(5) identify how many individuals were removed from the DD Waiting List during the 12 months covered by the report, why they were removed from the list, and how long the individuals had been Wait for services or supports before they were removed from the list;

(6) list the number of individuals who have been on the DD Waiting List for 90 days or more with an account of the department's steps to regularly review each individual's status while waiting for services or supports;

(7) report annual data from the Department of Education and Early Development about the number of students in Special Education with developmental disabilities graduating from high school, dropping out of high school before reaching age 22, or reaching age 22 without graduating from high school; and

(8) indicate that written or electronic copies of policies, manuals, and procedures used by the department to implement [AS 47.80.100](#) - 47.80.170 are available. Written or electronic copies of policies, manuals, and procedures used by the department to implement AS 47.80.100 – 47.80.170 are available by request.

# ELIGIBILITY DETERMINATION AND REQUEST FOR SERVICES

## Department of Health and Social Services Division of Senior and Disabilities Services

**FOR ASSISTANCE IN FILLING OUT THIS FORM, Call the Program Specialist Nearest You:**

<b>Anchorage Office/Anchorage Phone:</b>	<b>269-3600; 1-800-770-3930; TTY 269-3624</b>
<b>Northern Office/Fairbanks Phone:</b>	<b>451-5045; 1-800-770-1672; TTY 451-5093</b>
<b>Southcentral Office/Wasilla Phone:</b>	<b>352-6301; 1-800-755-0712; TTY 352-6333</b>
<b>Southeast Office/Juneau Phone:</b>	<b>465-3370; 1-800-465-4828; TTY 465-2225</b>

### A. INFORMATION ON THE PERSON NEEDING SERVICES

1. Name: \_\_\_\_\_  
Last Name First Name M.I.
2. Address: \_\_\_\_\_  
City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_
3. Telephone Number: (\_\_\_\_\_) \_\_\_\_\_
4. Sex: ☐ Male ☐ Female
5. Marital Status: ☐ Never Married ☐ Married ☐ Divorced
6. Date of Birth: \_\_\_\_\_ Place of Birth: \_\_\_\_\_
7. SSN: \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_
8. Ethnicity: ☐ Alaska Native ☐ Caucasian  
☐ African-American ☐ Hispanic  
☐ Asian ☐ Other
9. Name of Legal Guardian: \_\_\_\_\_
10. Guardian's Address: \_\_\_\_\_  
City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_
11. Home Telephone: \_\_\_\_\_ Work Telephone: \_\_\_\_\_

**If determined eligible to receive Developmental Disability Services do you want to be added to the DD Waiting List? \_\_\_\_Yes \_\_\_\_No**

If yes, when? \_\_\_\_\_  
Date

If you would like to be added to the DD Waiting List, please fill out a DD Waiting List Criteria Assessment **in addition** to this form.

**B. SERVICE INFORMATION**

**All questions in this section are directed toward the person with disabilities who is requesting service.**

What services or supports do you need? \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

1. How soon do you need these services? Circle one:

Now	6 months	1 year	2 years
3 years	4 years	5 years	Other _____

Specify Date

2. What agencies or people in your community are helping you now? \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

3. Why are you requesting services at this time? \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

4. In what community will you need the services and supports you are requesting?

\_\_\_\_\_  
\_\_\_\_\_

5. Are there any particular agencies or people you would like to provide the services and supports you need? Are there any special conditions you would like to place in these services. \_\_\_\_\_

\_\_\_\_\_

6. Please check if the person needing services has received any of the following in the past six months.

- |                          |                                    |                 |
|--------------------------|------------------------------------|-----------------|
| <input type="checkbox"/> | Medicaid coupons                   |                 |
| <input type="checkbox"/> | SSI (Supplemental Security Income) | Amount \$ _____ |
| <input type="checkbox"/> | AD Aid to the Disabled             | Amount \$ _____ |
| <input type="checkbox"/> | Public Assistance                  | Amount \$ _____ |
| <input type="checkbox"/> | Food Stamps                        |                 |

C. **FUNCTIONAL ASSESSMENT**

Describe the applicant's ability to perform the skills in the following areas of major life activity compared to a person of the same age who does not experience a disability (e.g., compare and contrast levels of independence, need for on-going support and assistance, etc.)

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**1. SELF CARE**

What kind of assistance do you need, if any, for eating, dressing and toileting?

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**2. EXPRESSIVE & RECEPTIVE LANGUAGE**

What is your primary means of communicating with others? Describe any special supports or assistance you use for communicating with other people.

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**3. LEARNING**

What is the easiest way for you to learn new information and skills? Do you need extra help or support to make learning easier?

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**4. MOBILITY**

Describe any special equipment or assistance you need to move from one place to another at home, work, school, or in the community.

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**5. SELF DIRECTION**

What kinds of decisions are you able to make on your own? Describe any support or assistance you rely on to help make decisions, or get through your daily routine.

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- ☐ 6. CAPACITY FOR INDEPENDENT LIVING  
(Only applies if age 16 years or older)

What supports do you need to live independently in your own home, do your own shopping, meal preparation, home maintenance, scheduling and keeping appointments, etc.

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- ☐ 7. CAPACITY FOR ECONOMIC SUFFICIENCY  
(Only applies if age 16 years or older)

What assistance is necessary for you to support yourself with income from a job, or through subsistence activities?

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**D. ELIGIBILITY FOR SERVICES**

In order to assist in determining eligibility, please attach assessments, medical evaluations, etc.

For determining the eligibility for people six years and older, a recent school or psychological evaluation that includes a full scale I.Q. score (for people who experience mental retardation) is requested. For disabilities other than mental retardation, a physician' statement or evaluation may be used, as well as Special Education evaluations, and/or other comprehensive evaluations that document the existence of a disability which occurred prior to the age of 22 and is likely to last indefinitely.

If you do not have a comprehensive evaluation available, but have had one in the past, please fill out the information release on the last page of this packet so the Division may obtain the information.

**\*\* Applications submitted without supporting documentation of disability, or a signed information release cannot be processed within normal time frames, and may be returned.**

1. Please list any mental or physical impairment or combination of physical and mental impairments that have occurred before age 22, that are likely to continue indefinitely, and result in substantial functional limitations in three or more areas of major life activity.

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**E. INFORMATION RELEASE AND ASSURANCES**

You will need to complete a separate information release for each agency or individual you wish the Division to obtain information from. An information release form is attached. Place the name and address of the agency or individual you wish the Division to receive information from in the area designated "To:". Specify the information to be released by dating and initialing the appropriate boxes. Sign the form and return it with the application to the address of the nearest Regional Program Specialist.

Note: Failure to provide consent to release information will not prohibit provision of services to eligible individuals. It may however substantially delay the Division's determination of eligibility.

I certify that the information contained herein is correct and accurate to the best of my knowledge.

Applicant or Guardian Signature: \_\_\_\_\_

Date: \_\_\_\_\_

The individual experiencing a disability or guardian will receive a written determination of eligibility for services and confirmation that services will be provided, or that the individual's name was placed on a waiting list for services. If you feel an error was made in the eligibility determination, contact the Division of Senior and Disabilities Services, P.O. Box 110680, Juneau, AK 99811-0680, or telephone (907) 465-3370 within 30 days of receipt of the written eligibility determination to initiate an appeal.

#### STATE USE ONLY

**DD Staff use:** MR ☐ Autism ☐ CP ☐ Epilepsy ☐

Eligible Per AS 47.80.900 Prior to 7/28/92 Yes ☐ No ☐

	<u>ICD-9-CODE</u>					<u>Date of Onset</u>		
	M	D	Y			M	D	Y
1.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Applicant Name: \_\_\_\_\_

Date Determined Eligible: \_\_\_\_\_

Date Eligibility Denied: \_\_\_\_\_

Developmental Disabilities

Regional Coordinator Signature: \_\_\_\_\_

Date Eligibility Determination Letter Sent: \_\_\_\_\_

Placed on Applicant File List: Yes ☐ No ☐

**Attachment B**

## Sample

Date

Address

Re: Eligibility Determination and Request for Services for (name, DOB)

Dear:

I have reviewed your application for developmental disability services. Based on the documentation provided, I find that you do experience a substantial developmental disability as defined by Alaska Statute 47.80.900. Therefore, you are eligible to receive services through the Division of Mental Health and Developmental Disabilities. I am including a copy of the application for your records.

A DD Waiting List Criteria Assessment has been completed on your behalf for [Services]. This assessment will allow your name to be added to the DD Waiting List for consideration of services once funding is made available. Please be advised that it may be quite some time before your name is selected.

I have enclosed a listing of developmental disability service providers. I strongly encourage you to telephone each one and familiarize yourself with their services. This is very important for two main reasons:

1. Each provider may assist with advocacy and referral services, crisis response, and acquisition of necessary adaptive equipment. They may also be able to offer you other types of supports depending on the resources allowed for in their grant with the Division.
2. I will notify you when you are selected from the DD Waiting List. At that time you will need to select one or more agencies to work with to develop and implement your support plan. Familiarizing yourself with the agencies now will prepare you for making an informed choice in the future.

Be assured that agencies across the state provide similar services in other locations. Regional listings of developmental disabilities providers are available on request. If you or your family is planning a move within Alaska, please let me know and I will gladly assist you.

If I can be of further assistance, please do not hesitate to call me at the above number.

Sincerely,

[Regional Program Specialist]

cc: [Agency of record]

**Attachment C**

## DD WAITING LIST CRITERIA ASSESSMENT

**Check One:**

\_\_\_New Assessment      \_\_\_Re-Assessment      Date:\_\_\_

**SCORE****Check One Regional Office:**

\_\_\_ARO (Terry Hoke, Patricia Johnsen, Clark Stanton)

\_\_\_SERO (Laurie Peterson)

\_\_\_NRO (Rebecca Hilgendorf)

\_\_\_SCRO (Laura Sasseen)

**NAME:****BIRTH DATE:****ADDRESS:**

Street \_\_\_\_\_  
City \_\_\_\_\_  
State \_\_\_\_\_ Zip \_\_\_\_\_

**GENDER:****PHONE: (home)****PHONE: (work)****LEGAL GUARDIAN:** (verify court appointment)**ADDRESS:**

Street \_\_\_\_\_  
City \_\_\_\_\_  
State \_\_\_\_\_ Zip \_\_\_\_\_

**PHONE: (home)****PHONE: (work)****INFORMANT FOR THIS ASSESSMENT:**

RELATIONSHIP TO INDIVIDUAL:

PHONE:

Services Desired:	Please list all desired services now and in the future along with the priority and date	Priority #	MO/YY	Internal use: Code

**Attachment D**

## SERVICES DESIRED IN THE FUTURE

DSDS requires that the family member/informant completing this assessment include a comment for each question answered yes.

### POINTS

#### A. Time

\_\_\_\_\_ Date of application for desired services

NOTE: Not necessarily the same date as application for eligibility.

**One point per month up to a maximum of 60 points.**

#### B. Community Service Needs

\_\_\_\_\_ 1. Is the individual:

--- A documented threat to himself/herself or others,

Yes \_\_\_\_\_ No \_\_\_\_\_ Or \_\_\_\_\_

--- Homeless,

Yes \_\_\_\_\_ No \_\_\_\_\_ or \_\_\_\_\_

--- Prioritized to be served by a legislative or judicial mandate?

Yes \_\_\_\_\_ No \_\_\_\_\_ Or \_\_\_\_\_

**Additional information:**

---

### **100 points**

List other service options that have been tried.

\_\_\_\_\_ 2. Is the individual:

--- Institutionalized in an ICF or hospital,

Yes \_\_\_\_\_ No \_\_\_\_\_ If Yes, how long? \_\_\_\_\_ or \_\_\_\_\_

--- Wanting to work and capable of employment and without a job,

Yes \_\_\_\_\_ No \_\_\_\_\_

--- Receiving either child or adult protective services?

Yes \_\_\_\_\_ No \_\_\_\_\_

**Additional information:**

---

**40 Points plus one point for each year that a person presently residing in an ICF or hospital has been institutionalized.**

\_\_\_\_\_ 3. Is the individual at risk of placement in a less normative environment unless services are provided?

Yes \_\_\_\_\_ No \_\_\_\_\_ If yes, where: \_\_\_\_\_

**Additional information**

---

### **30 Points**

IF YES, is the risk due to:

\_\_\_\_\_ a) his/her medical needs?

Yes \_\_\_\_\_ No \_\_\_\_\_

**Additional information**

**5 Points**

\_\_\_\_\_ b) the caregiver's age or acute medical/psychological condition?  
Yes \_\_\_\_\_ No \_\_\_\_\_

**Additional information**

**5 Points**

\_\_\_\_\_ c) the need for a higher level of labor-intensive daily living support/services?  
Yes \_\_\_\_\_ No \_\_\_\_\_

**5 Points**

**Additional information**

\_\_\_\_\_ d) Episodic disruptive behaviors?  
Yes \_\_\_\_\_ No \_\_\_\_\_

**Additional information**

**5 Points**

\_\_\_\_\_ e) the need for an increased level of support/services in order to maintain employment?  
Yes \_\_\_\_\_ No \_\_\_\_\_

**Additional information**

**5 Points**

\_\_\_\_\_ 4. Is the individual in an environment where the stress is so great that relief/services are needed to prevent further deterioration of the situation? Describe under comment section.  
Yes \_\_\_\_\_ No \_\_\_\_\_

**Additional information**

**30 Points**

\_\_\_\_\_ 5. Does the individual have adequate formal or informal supports in place?  
Yes \_\_\_\_\_ No \_\_\_\_\_  
Are the additional services desired?  
Yes \_\_\_\_\_ No \_\_\_\_\_  
IF NO, may individual's name be removed from the waiting list?  
Yes \_\_\_\_\_ No \_\_\_\_\_

**Additional information**

**NOTE: Points awarded in this category only if none have been awarded in prior categories.**

**TOTAL**

**Additional information to support the previous 5 questions.**

**COMMENTS:**

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## Sample

Dear Ms Ricardo:

Thank you for asking about Ricky's rank on the DD Waiting List. I hope the services that he is receiving from your community provider are helpful while you wait for information about future services.

Ricky's Waiting List score is figured by adding the Base Score that comes from the assessment of need and the timed score that is computed based upon the length of time a person is on the Waiting List. The maximum points that can result from the Assessment of Need are 225. For a total not to exceed 60 points, an applicant receives one point for each month they are on the list. Total scores for the current applicants range from a low of 20 to high of 280 points.

Ricky's Base Score is 98 and his Timed Score is 60 points for a total of 158 points. With number 1 as the top, he ranks number 302 on the current list of 1233 people.

Each person's standing on the list is relative to the scores of all others on the list. Consequently, a person's rank order can change depending on the relative needs of others on the list. Simply put, Ricky's rank on the list may change should new applicants with higher needs be placed on the list.

I wish I could tell you exactly when Ricky will be selected from the list for more comprehensive services. But, we can't. We are attempting to move people off the DD Waiting List at a reasonable pace by selecting new individuals from the list as we identify new resources during the year. The number of people selected is limited by the amount of appropriation for services passed by the legislature.

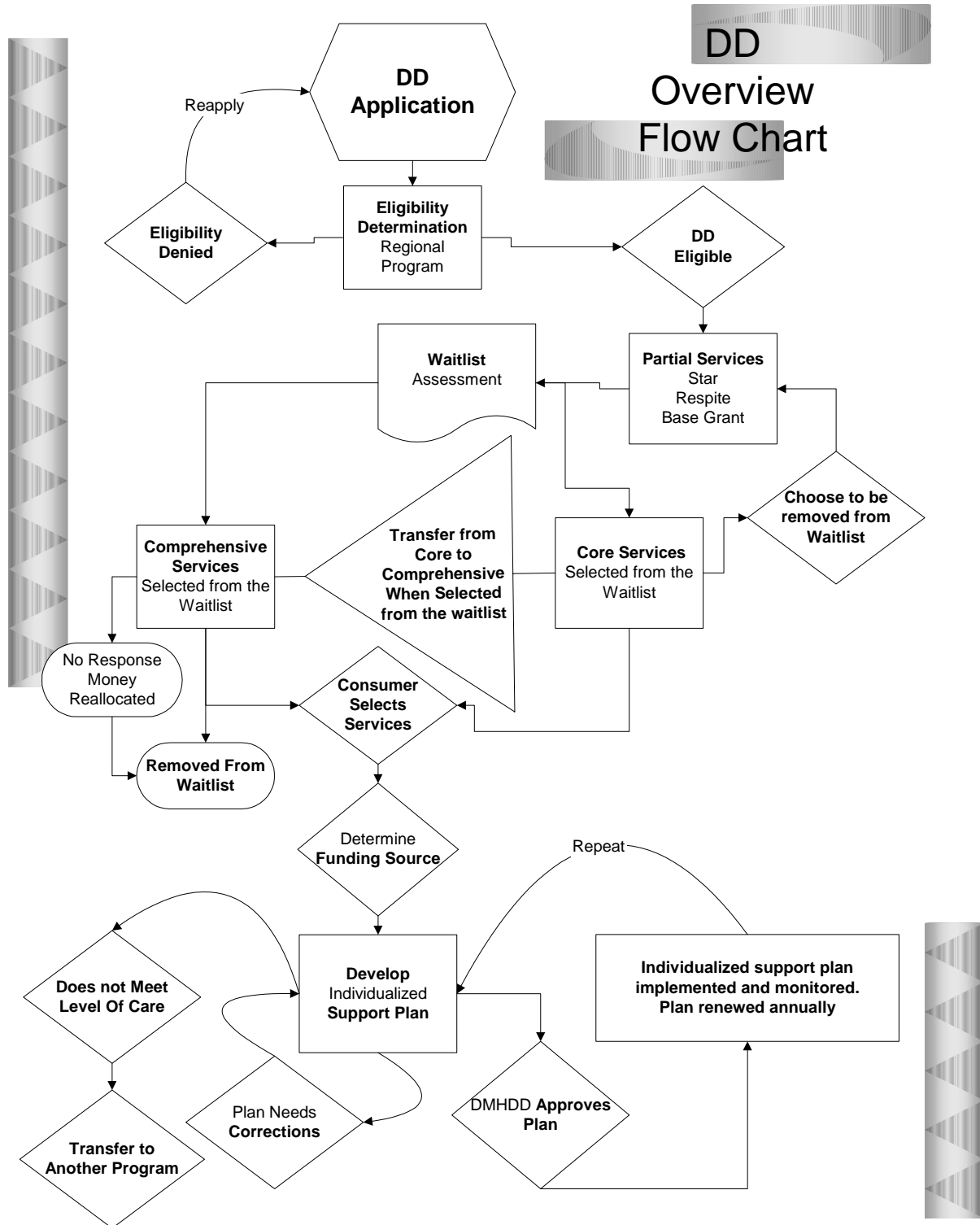
If you feel Ricky's needs have changed or there is an immediate need for services since the last time you submitted a Waiting List Assessment, contact the Anchorage Regional Office at 269 3666 and ask to speak to a DD Program Specialist or contact the STAR Project *at a local DD provider*.

If you wish to appeal the score or standing on the DD Waiting List, you may contact David Maltman, DD Program Administrator, Division of Senior and Disabilities Services, P. O. Box 110680, Juneau, Alaska 99801-0680 or call him at 907 465-3370.

Sincerely,

Appropriate DD Program Staff

**Attachment E**





February 27, 2004

Subject: Developmental Disability Waiting List

Dear Waiting List Applicant:

The Division of Senior and Disabilities Services (DSDS) is updating information on the waiting list. You are receiving this letter because you or someone represented by you is on the waiting list and we want to be sure we have correct information to use in selecting the next person on the list for services. **In order to remain on the list, you need to return the enclosed survey by April 15, 2004.**

We appreciate your time in completing and returning the survey. As you know, the State of Alaska is facing critical reductions in funding for all areas of service. Therefore, it is extremely important for DSDS to have accurate information to determine the level of service required to meet your future needs. **Your response to this survey may determine when you access services, therefore, it is critical that you carefully read and answer each question to the best of your ability.** Please return the survey in the enclosed self-addressed, stamped envelope. If you do not return the survey, we must assume that you no longer need services or you have moved from Alaska and are no longer eligible to receive state services. Failure to return the survey by **April 15, 2004** will result in your name being taken off the waiting list.

Thank you in advance for taking the time to return the survey. We have produced a report on the waiting list that you can request by calling 907-465-3165. Or, you may read a copy of the report on our website at the following address:

<http://www.hss.state.ak.us/dsds/dd/pdfs/Waitlist%20Report%2002%20final.pdf>

The report explains why there is a waiting list, how it is managed, why it is growing, and it gives demographic information about the ages, sex, and needs of those on the list.

If you have any questions or need assistance completing this survey, please contact Kristie Swanson at 1-907-465-3165 or 1-866-465-3165.

Sincerely,

Steven P. Ashman  
Director

Enclosure

**Attachment G**

## DEVELOPMENTAL DISABILITY WAITING LIST SURVEY

Name of Recipient: \_\_\_\_\_  
Last First Middle

Initial \_\_\_\_\_

Address: \_\_\_\_\_  
Street or P.O. Box City State Zip

Is this a new address? No \_\_\_\_\_ Yes \_\_\_\_\_

Date of Birth: \_\_\_\_\_ Sex: Female ☐ Male ☐

Telephone: Home: (907) \_\_\_\_\_ Work: (907) \_\_\_\_\_

Are you currently receiving services? No \_\_\_\_\_ Yes \_\_\_\_\_

(Please include any Indian health, mental health, school district (OT, PT, ST) or other community services such as Special Olympics, Challenge, vocational rehabilitation and core services.)

If yes, please list the type of services, provider and number of hours/funding you are receiving.

Type of Service: week	Provider:	Number of hours per or amount of funding:
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

Are you eligible for Indian Health Services benefits? No \_\_\_\_\_ Yes \_\_\_\_\_ If yes, you may be able to receive waiver services through an Indian Health Service program. DSDS will contact with further information.

Are you currently receiving Medicaid? No \_\_\_\_\_ Yes \_\_\_\_\_ If yes, list provider #: \_\_\_\_\_

Do you wish to remain on the waiting list? No \_\_\_\_\_ Yes \_\_\_\_\_

Have your needs changed since your application for services? No \_\_\_\_\_ Yes \_\_\_\_\_

If yes, please complete a Waitlist Reassessment Form. Describe the change: \_\_\_\_\_  
\_\_\_\_\_

Are you in need of residential care now? No\_\_\_\_Yes\_\_\_\_ If no, when you do  
anticipate needing residential care? \_\_\_\_\_

List name of person completing this survey: \_\_\_\_\_

Relationship to recipient: \_\_\_\_\_

Please return this survey to: DSDS, P.O. Box 110680, Juneau, AK 99811-0680